



**Annual General Meeting  
The United Kingdom Primary Immunodeficiency Network (UKPIN)  
which took place on  
Wednesday 14<sup>th</sup> November 2018  
at  
Citadines, Holborn**

Attendance:

UKPIN trustees: Sarah Denman (SD), Sinisa Savic (SS), Ravishankar Sargur (RS), Jill Edmonds (JE), Tomaz Garcez (TG), Kimberley Gilmour (KG), Rashmi Jain (RJ), Peter Arkwright (PA), Austen Worth (AW), Suzy Elcombe (SE), Claire Bethune (CB)

UKPIN members: Declan Bostock (DB)

BSI: Otto Balsiger (OB), Kajal Tanna (KT)

**1. Welcome**

Tomaz Garcez (TG), Chairman, UKPIN, welcomed everyone to the AGM.

**2. Review of previous minutes**

No matters arising

**3. Chair Report**

Trustees

Current trustees updated:

Name	Position	Role	Start Term Date	Demit Date
<i>Peter Arkwright</i>	<i>Member</i>	<i>Information</i>	<i>2015</i>	<i>2018</i>
<i>Claire Bethune</i>	<i>Honorary Secretary</i>	<i>Accreditation; Guidelines</i>	<i>2011</i>	<i>2018*</i>
<i>Christine Symons</i>	<i>Member</i>		<i>2015</i>	<i>2018</i>
<b>Bill Egner</b>	<b>Member</b>		<b>2015</b>	<b>2018</b>

Tomaz Garcez	Chair		2014	2018
<b>Gavin Spickett</b>	<b>Member</b>		<b>2015</b>	<b>2018</b>
Kimberly Gilmour	Member	UKPIN Meeting	2015	2018
Rashmi Jain	Treasurer		2014	2018
Ravishankar Sargur	Member		2014	2020*
Suzy Elcombe	Trainee Member			2019*
<b>Austen Worth</b>	<b>Member</b>		<b>2018</b>	<b>2021</b>
<b>Jill Edmonds</b>	<b>Member</b>		<b>2018</b>	<b>2021</b>
<b>Lisa Devlin</b>	<b>Member</b>		<b>2018</b>	<b>2021</b>
<b>Sarah Denman</b>	<b>Member</b>		<b>2018</b>	<b>2021</b>
<b>Siniša Savić</b>	<b>Member</b>		<b>2018</b>	<b>2021</b>

New members:

Zohreh Nademi

Catherine O'Sullivan

Angela Stevens

John Dempster

Ariharan Anantharachagan

Siraj Misbah

Venetia Bigley

Karen Henderson

Louise Greathead

Florence Manyika

Ina Schim van der Loeff

Fan Cheng

Lavanya Diwakar

WANITA VERMAAK

Adrian Shields

Smita Y Patel

Update provided on the charitable objects of UKPIN and progress towards them:

- Objects are for advancing care for PID including:
  - Develop best practice approaches to diagnosis and management
  - Guideline development
  - Registry
  - Education
- Can only be changed with written approval of the Commission

- Much more detail in the constitution
- Accreditation & census report to follow
- Guidelines development report to follow
- Registry report to follow
- UKPIN Meeting report to follow
- Financial report to follow

#### Summary of work with BSI:

- BSI agreement building collaborative work
  - Meeting
  - Guidelines
  - Lobbying / consultation responses
  - To be considered
    - Education
    - Patient advocacy

#### Update provided on immunoglobulin framework:

- Letter to NHS England
  - Co-signed by:
    - BSI
    - Patient group
    - Nursing group
- Response to be finalised for public circulation in next week

#### Treasurers report

RJ gave a short presentation on the UKPIN finances; net assets have risen from £60k to £95k this year; this was following an increase in net income of £33k. At the end of October 2018, the bank had a healthy balance of £89k.

#### Accreditation, guidelines & census

34 out of 36 centres are registered and 11 are accredited; QPIDS standards have been developed from UKPIN standards. The aim for next year is for 50% of services to have been accredited by the UKPIN meeting in 2019, and several visits are already booked.

The 2017 census has been circulated to participating centres and 2018 responses have now been collected; the report is in preparation. 2018 staffing results were as follows; 8 unfilled posts, 14 retiring in next few years.

The first guidelines have been written, and the same process will apply for creating and implementing the next guidelines.

Data from the 2018 census presented. Data available on request.

## UKPID Registry

There were 6,675 patients entered in total, and a 2018 joint publication with MDSAS, with APDS having a joint publication with ESID. The registry was then successfully adopted by NIHR LCRN and has been since August 2018. Sites should now have access to a local CRN resource to support recruitment and data entry

## UKPID 2018

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## Website

There were around 2,000 views per month which then increased to 5,000 around the time of the UKPIN meeting, and most of these views are either from the UK or USA. Half of views were done via people's phone, and half via pc. The main areas that people visit on the website are meetings, registry, membership and guidelines.

## UKPIN meeting 2019

The dates have been decided for 5<sup>th</sup> & 6<sup>th</sup> December 2019. The first day plenary sessions will be shared with BSI, similar to 2017. There will be more focus on UK based clinical practice.

## The future

### TG summarised future plans:

- Support QPIDs and the annual census
- Continue development of clinical guidelines
- Develop registry with level 2 data
- Produce joint registry and Ig database reports
- Continue to support education
- Consider closer collaboration with other organisations with aligned objects
- Presenting a voice for HCP in PID
- HAE Network

## The vision

### TG summarised UKPIN vision

- Grow membership
- Keep multi-professional
- Develop registry
- Education
- Guidelines
- Ensure better care
- Ensure no Brexit impact on collaboration with ESID etc.

TG thanked sponsors and closed the meeting